

March 4, 2014

Re: In support of SB-325 (LCO 1369)- An Act Concerning Medicaid Recipients With Complex Medical Needs

Dear Human Services Committee Members,

Hello my name is Bill Mancini. I live in West Hartford and have been a resident of Connecticut for 40 years. I teach Special Education in Bristol and am President of the National Spinal Cord Injury Association, Connecticut Chapter (NSCIA CT Chapter) in Wallingford. I'm here to support the passage of Senate Bill SB 325, what I call the Complex Rehab Technology (CRT) bill.

The NSCIA CT Chapter consists of close to 500 individuals whose lives have been impacted by a spinal cord injury. This important legislation needs to be passed in order to help people with a disability get specialized equipment. Having access to CRT enables me to be an active member of my community.

I have had a spinal cord injury since 1993. I was not born disabled. My injury occurred when I had a stroke to my spinal cord at the age of 20. Prior to my injury I attended college, worked and had a very active social life. You could imagine the thoughts that were in my head when my doctors told me I was not going to walk and be confined to a wheelchair for the rest of my life. The thoughts still give me the chills to this day. As I went through three months of rehab, my thoughts changed as I was exposed to more CRT.

I currently use a rigid frame wheelchair which has a specialized seat cushion. The chair is very different than your basic hospital chair. It's much lighter and is sized and individually set up to maximize my ability to get around every day by using my arms instead of my legs. It's also designed to come apart with ease in order to allow me to access my vehicle. These accommodations were discussed with me by a trained professional from the rehab hospital and a qualified complex rehab technology technician. Both professionals discussed in great detail what CRT would benefit me the most. This is not something that your basic drug store pharmacist has the knowledge, training or even takes the time to help someone figure out. Items addressed by them were the importance of having the correct chair to make sure I don't injure my shoulders from pushing incorrectly and pressure sores by either sitting in the incorrect position or a chair that is either too small or too big. The important thing is that their knowledge and expertise helped me to select the appropriate CRT in order to make me the most independent leaving the hospital.

Even though I am confined to a wheelchair, I teach students with attentional, learning, behavioral and cognitive deficits at the elementary level. I could not imagine performing my daily teaching duties if I was not able to have access to the kind of wheelchair I currently use. In addition, I could imagine being forced to work out of a piece of used equipment. I have confidence in my chairs and know when something is not right and needs to be repaired. CRT companies have been a great support to me in being able to get to work each day. They are able

to come to my work and make repairs as needed. Having this type of chair has led me to lead the same and even better life than before I was injured.

I would also like to add, that as a SPED teacher I am a bit concerned that some of the CRT that I had an opportunity to access will not be there for my students in the future. Technology is always changing. Whether it is voice activated software or specialized sit-and-stand chairs technology is designed to make people independent and active members of their community. Whether going to school or entering the workforce legislation needs to be passed to keep up with the advances in technology, not to stunt it and hold people back. The disability community needs to be provided with the CRT needed to leave the house not get trapped in. Passing the Complex Rehab Technology bill is a good start.

CRT is "complex". Each piece of equipment is designed and meant for the individual needs of that one person. It is like the person's fingerprint. Its unique it meet the individual needs of the consumer. As a SPED teacher my job is find an implement the appropriate accommodations of my students. This cannot be done if the professionals are not given the opportunity to select and make the needed adjustments that only they have the knowledge to do so.

This specialized equipment is vital to children and adults with disabilities. It helps reduce healthcare costs and provides independence and safety. The Complex Rehab Technology bill will help improve people's access to specialized equipment and add safeguards to make sure only qualified companies provide these products and services.

Please pass Senate Bill 325. Thank your for the opportunity to speak to you today.

Bill Mancini President NSCIA CT Chapter